

# **Exhibit 9**

## SaveonSP's Copay Maximizer Failed Me: A Patient's Perspective

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### A Patient's Perspective

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Today's guest post comes from Anndi McAfee, a successful voice over artist. Check out her impressive IMDB credits. Your kids have definitely heard her voice.

Anndi also suffers from a rare disease and requires treatment with an orphan drug. Below, she shares her troubling experiences with SaveonSP, the mysterious company behind Express Scripts' copay maximizer program. (ICYMI, I profiled SaveonSP in May.)

Anndi's story illustrates how a patient taking a specialty drug can lose out, even as others—her health plan, its PBM, and a sketchy intermediary—profit from a manufacturer's patient support funds. I suspect that very few patients with similarly complex diseases are as savvy and persistent as Anndi has been.

Read on for her disturbing story. You can reach Anndi via her professional page or on LinkedIn.

### SaveonSP's Copay Maximizer Failed Me: A Patient's Perspective

By Anndi McAfee



I tell people I have two full-time careers: I'm a voice over artist ... and chronic disease manager.

I was diagnosed with a super-rare chronic disease in 1997, just days before my 18th birthday. I was immediately thrust into the world of disease management—and into the supply chain that would get the only drug available into my body, so I could live a “normal” life.

At the time, this drug was the third most expensive on the planet, and my insurance plan tried to deny my care. That was the first and only battle my parents would fight (and win) on my behalf. By the time I started receiving treatment for the disease, I was an adult.

Since my diagnosis, I have spent my life managing the debilitating symptoms of my disease and the huge challenge of receiving a biologic that must be specifically mixed and then delivered intravenously by an RN for three hours every other week. I somehow managed all this while balancing the equation of expending the precious energy needed to acquire enough work to qualify for my union health insurance—and of expending an equal amount of energy advocating for my insurance benefits to be administered properly through multiple healthcare providers.

My “second career” has consisted of fighting multiple disease-related claim denials by my insurance plan (I won every appeal), multiple transgressions by my specialty pharmacy (I won a HIPAA violation against them), a months-long drug shortage, and a multitude of other struggles that have led to emotional, physical, and mental breakdowns.

Now that I've painted a very brief picture of life as a rare disease patient, I want to talk about the most recent health care disruption in my life: a copay maximizer program.

This September, I received a frantic alert from my drug manufacturer that all of the money allotted me through its co-pay assistance program was gone—due to a copay maximizer program called SaveonSP. I was astonished. I had been on a copay assistance program

ever since I had begun treatment, and had never needed more than approximately 10 percent of the available money to cover my copays.

Feeling that familiar sense of anxiety, I reached out to SaveonSP. It confirmed the money had been spent. In December of 2019, SaveonSP had called me to enroll me voluntarily in its program for 2020, which I agreed to. But by September of 2020, this call had escaped my mind and so had SaveonSP.

Here's where things in my second career get complicated. My pharmacy benefit copay is \$250 for every 90-day supply. Consequently, SaveonSP billed the drug manufacturer copay assistance program every 90 days until it captured all of my copay assistance money.

Unfortunately, SaveonSP had billed for and received all available copay assistance money from the drug manufacturer before I had received all of the shipments for the year. I had no idea how or why that happened.

Feeling overwhelmed, I panicked and went on the warpath. I called anyone and everyone, everywhere—multiple times.

After multiple calls, SaveonSP has assured me that despite all this, I will still not pay a dime out of pocket and will receive my shipment without a hitch. Apparently, it will now bill my health plan directly for my prescriptions. I am still unsure as to why another third party company has been added to my drug supply chain.

I also cannot get anyone at Express Scripts, the pharmacy benefit manager for my plan, to explain why my first-line orphan drug is on the “non-essential health benefit” list it generated for enrollment into SaveonSP. Nor will anyone at Express Scripts explain why the other three first-line orphan drugs indicated for the treatment of my disease don’t appear on this list. (Incidentally, my “non-essential” drug is on the preferred formulary of Express Scripts.) Is Express Scripts billing the manufacturer copay assistance program directly for the other three drugs, as they always have? What happens if I refuse to enroll in a copay maximizer program?

If SaveonSP had not used all of my money, I probably would have continued on in sweet blissful ignorance. But here I am again, expending precious time and energy to ensure that my drug gets into my body.

I will probably have to go through this all over again in January, when my pharmacy benefit manager switches to CVS. Its copay maximizer program, PrudentRx, boasts automatic enrollment and the same “non-essential health benefit” list.

And so my second career as a chronic disease manager continues to flourish.